


**PROBLEMS OF PARENTS WITH A BABY IN A  
NEWBORN INTENSIVE CARE UNIT  
AND  
IMPLICATIONS FOR NURSING**

**AN HONORS THESIS (ID 499)**

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## PREFACE

These words were written by a teenage mother whose baby was in a Newborn Intensive Care Unit in Texas:

### THE LAND OF MACHINES

"Sitting here in the land of machines  
Holding the hands of the ones we love  
A beeper sounds, a red light flashes  
And fear runs away with our hearts.

Those strange incomprehensible machines  
Made up of buttons and switches and flashing lights  
And buzzers beeping to every tune  
Telling us how strongly our loved one lives.

To sit there and watch helplessly  
As the blood flows red  
As the heart stops beating  
As the lungs stop breathing  
Is worse than any death.

To hold the hands of the ones we love.  
As the veins and arteries deteriorate  
As the sores grow worse  
As the eyes grow blind and the bones grow weak  
Is worse than any fate.

We cry and pray and try to be strong  
And we put on an act for the world  
While inside we are filled with pain  
As we sit there holding the hands of the ones we love  
While fear runs away with our hearts  
Sitting in the land of machines."

Michele Lynn Smith  
(Marshall, 1982, 21-22).

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## **INTRODUCTION**

The birth of a baby is perceived almost universally as a joyous occasion after many months of anticipation and preparation. For thousands of individuals this joyous occasion turns to sorrow as they realize their child is not of the optimal health they had hoped it would be. For some this means their child will be born one, two, or even three months early and require several months of tedious hospitalization, often times in another city many miles away. For others the reality is that their newborn child suffers from a congenital birth defect or defects—some repairable and others incompatible with life. Whether the baby requires hospitalization for three days or three months, the parents are presented with a situation they have probably not experienced before nor are they adequately prepared to cope. Thus, a series of crises begins for these parents from the time of birth until well after the baby is discharged for home, or in less fortunate cases, dies.

Neonatal care has made great strides since its inception twenty to thirty years ago. (McGovern, 1984, 128). Great technological advances have occurred in such areas as developmental physiology and biochemistry which have been translated into improved medical and nursing care for these neonates. Treatment of low birth weight babies continues to make medical history. The weight limit of survival continues to be pushed

lower and lower. McGovern states, "Many units quote survival rates of 85% in 1000 gram infants and even more remarkable is the 60% survival rate of babies 750 grams and perhaps only 26 weeks gestation. " These great strides in medical treatment have resulted in more babies living that would have had relatively little chance of survival a few years ago. Many of these babies require extensive treatment even after their release from the NICU. Thus, the struggle for the parents continues.

The purpose of this thesis is to present a synthesis of the current literature and research published regarding the problems of parents with a child in a newborn intensive care unit (NICU). It is an outgrowth of my experience completing a Summer Practicum in the Newborn Intensive Care Unit of James Witcomb Riley Hospital for Children in Indianapolis, Indiana, from June to August, 1985. During these three months I witnessed not only the medical problems of these critically ill neonates, but also the emotional, financial, and familial stressors placed on the lives of their parents. In this paper I will describe crises encountered by these individuals, their common emotional reactions to them, the effect separation of parents and newborn has on the bonding process, financial difficulties encountered by these parents, support groups available to these families, and finally techniques nurses can utilize to aid the parents during this period.

## **OVERVIEW**

A Newborn Intensive Care Unit (NICU), also referred to as a Neonatal Intensive Care Unit, Special Care Nursery, or Special Care Baby Unit is

generally an overwhelming and intense environment. Isolettes (incubators), open heated cribs, and bassinets appear scattered throughout the units' room or rooms containing all different sizes and shapes of newborns. A complex array of monitors provide the area with a melodious concert of beeps, buzzes, and bells that becomes the characteristic sound of the unit. These monitors give a continuous recording of heart and respiratory rate and pattern and the concentration of oxygen the baby is receiving. Many of the infants' blood pressures are being recorded by non-invasive automatic blood pressure monitors.

Due to a variety of respiratory or neurological causes, many of the neonates in the NICU are being assisted to breathe by a respirator or ventilator which is connected to an endotracheal tube (a tube inserted into the baby's trachea through the mouth) or a tracheostomy (a surgical hole created on the outside of the neck directly into the trachea). This machine confirms its presence in the NICU with a constant hissing noise intensifying during each inspiration. Occasionally an alarm from the ventilator will sound informing the caretaker that a leak or a blockage exists somewhere in the line. Those neonates that are not ventilator dependent are often receiving some form of oxygen therapy. This may be in the form of an oxygen mask, hut, hood, or it may be blown into the isolette.

Several newborns at one time may be lying under "bili lights" for the treatment of neonatal jaundice. While this treatment is taking place the babies are stripped of all clothing, exposing as much skin surface area as possible, and their eyes are protected from the light with blindfolds. Almost all of the newborns at one time or another will be the recipients of

intravenous fluids, nutrition, or blood products through peripherally or centrally located intravenous lines. The babies often have nasopharyngeal tubes inserted through their noses or oropharyngeal tubes inserted through their mouths. These tubes terminate in their stomachs and are for feeding purposes.

This machinery-laden environment is constantly filled with medical personnel. Lab technicians are often present drawing blood for laboratory tests and radiology personnel are often visitors of the unit to take routine or specially ordered X-rays. A wide range of physicians, (including the attending residents, specialty physicians the baby may require, interns and medical students) are in and out of the unit. Nurses, the primary care givers 24 hours a day, are constantly in the unit or at the bedside performing treatments, feeding, cuddling, teaching the parents, and monitoring the baby's condition.

From this description it is obvious that the Newborn Intensive Care Unit is a very busy, congested place. The noise emitted from the monitors and personnel, not to mention the sometimes crying babies, is enough to overwhelm a newcomer to the unit. This, combined with the sophistication of the machinery and the unstable condition of many of the newborns is more than many parents new to the unit are prepared for.

Newborn babies are most often admitted to the NICU for low birth weight due to prematurity (gestation less than 37 weeks), respiratory distress syndrome, congenital anomalies, or for observation after high risk labor or delivery. Often times these babies are born in the same hospital and transferred to the NICU or brought to the NICU by the pediatrician attending the delivery. But many times the baby is



transferred from an outlying area to a tertiary care or regional center in a large metropolitan city soon after delivery or after a high risk condition is recognized. The average stay in a NICU for a neonate is 50 to 100 days. (McGovern, 1984, 29). The length of stay is so great because these infants are prone to a number of complications. This is especially true of the premature infant who must make up the weeks lost in the gestation process and whom must also fight the complications that arise as a result of the immaturity of his or her physiological systems.

### **CRISIS PERIODS FOR PARENTS OF SICK NEWBORNS**

When a woman's pregnancy is interrupted by a premature labor the first crisis for the family begins. (Tarbert, 1985, 20-21). There is a threat to the welfare of the baby, to the mother's health and to both their lives. Tarbert states, "The work of pregnancy is to deal with these feelings and to mature into the role of a mother. When this developmental process is interrupted, the woman experiences grief and depression." Four tasks that mothers experiencing premature delivery must master to establish a basis for a future healthy parent-child relationship have been described by Kaplan and Mason. (Thornton, 1985, p. 128). They are:

- (1) fearing and preparing for the loss of their infant but simultaneously hoping for his survival; this process begins at delivery;
- (2) facing and acknowledging feelings

of failure at not delivering a full term and healthy infant; (3) resuming the relationship with the infant that they have; this usually begins when the parents believe that their baby will survive, and (4) understanding how their baby differs from a full-term baby and also realizing that these differences may be temporary and will in time yield to more normal patterns.

Another crisis for the family of a defective baby occurs at birth when they realize that their child is not perfect. This is often recognized at birth by the parents as the child is whisked away to an NICU or is being intensively worked upon by the medical personnel present. The parents have planned for many months for "the perfect baby" and when the actual result is a malformed or a premature infant, a crisis involving grief and mourning ensues. These emotional reactions will be dealt with more specifically in the next section.

The next crisis period the family of the sick newborn experiences occurs if the infant must be transferred to a regional center for treatment. (Machan, 1983, 25). In some cases, the parents, especially the mother, are unable to see the infant prior to transfer. This escalates the fears and apprehensions the mother has regarding her infant. She often forms a mental picture of the baby from descriptions given her by the staff which in reality, is much worse than the baby actually appears. The father is usually able to travel the distance to see the baby but travel is often difficult for the mother who has just recently given birth, especially in the case of a cesarean section delivery.

The first contact the parents have with the infant in the NICU presents another potential crisis for the family. (McGovern, 1984, 128). Most of these babies are encased in the four walls of an incubator and are connected to an unlimited number of wires, tubes, and machinery. Parents are usually very distressed by this first sight of their baby but they also feel a sense of reassurance that all that is possible is being done for their baby.

Another crisis exists for the family of a high risk infant at the time of discharge. The transition from NICU to home can be overwhelming after a stormy course in the unit especially if there is a need for continued special care at home. (Lund, 1982, 49). Many parents "panic" just before discharge stating that they are not "ready" or their baby is not ready. Regardless of the amount and quality of preparation for discharge, many parents still feel overwhelmed. (Tarbert, 1985, 21). In follow-up studies parenting difficulties and "failure to thrive" have been reported. Research has shown that child abuse occurs more often to children who were prematurely born or suffered medical complications shortly after birth. (Everstine, 1983, 107). It is theorized that the separation of the mother and infant in those crucial first few weeks of life is related to this phenomena. Separation and its affects on parent-infant bonding will be discussed further in the next section.

In cases where the infant will be handicapped, another great burden is placed on the primary caregiver often resulting in the kind of stress and emotional reaction which often leads to severe depression and rejection of the child.(Tarbert, 1985, 21). In families where the infant suffers some form of neurological impairment the crisis continues for the

family. Depression, marital problems and financial difficulties have been a few of the recognized difficulties of parents coping with handicapped children at home. From the studies that have been completed it is obvious that these apprehensive parents may have good reason to be anxious about the affects taking their baby home may have on the family itself.

An obvious crisis occurs for the family that experiences neonatal death. (Mahan, 1983, 32). The death of a newborn whether it is stillborn or only lives a few hours or a few weeks is no less painful than the death of any other close relative. At the time of death, the family often feels that the overwhelming shock and sadness will never subside. Several common reactions to the death of a neonate have been cited in literature. Some parents may awaken at night thinking they hear crying from what would have been the baby's room. Mothers may believe they feel the baby kicking in their abdomens. Parents may find themselves preoccupied with the image of the baby. Some parents constantly look at pictures or other remembrance of the baby, while others store them away. Almost all parents report crying without provocation. Parents should be warned that these reactions are normal; otherwise, they may believe they are suffering from a serious psychological disorder.

Medical personnel working in a NICU, especially nurses, should be aware of these potential crises and ready to recognize them in the parents of the infants in the unit. Later in this paper, under the heading **NURSING IMPLICATIONS** specific strategies will be addressed that will enable nurses to help the families cope with these crises.

## COMMON PARENTAL EMOTIONAL REACTIONS

Several emotional reactions are common to almost all parents who experience the birth and hospitalization of a defective newborn. The first of these was eluded to earlier: grief. Almost all families suffer a grief reaction after the birth of a premature or malformed baby. (Thornton, 1984, 127). This grief is directly related to the loss of the parents' hoped for "perfect" baby. They grieve the fact that their child is not as they had expected and that they will not experience the normal joy involved with the birth of a baby. This joy will be overshadowed, at least temporarily, by fear, anxiety, and concern for their child's well-being.

Common to this reaction is a syndrome characterized by somatic distress of parents in repeated waves lasting twenty minutes to one hour. Frequently reported complaints during this period include tightness in the throat, shortness of breath, a need for sighing, an empty feeling the stomach, a lack of muscular power, and a subjective feeling described as "tension" or "mental pain." (Thornton, 1984, 127). The afflicted persons rarely are able to be warm in relationships with others. Because these reactions are difficult for people to handle they often appear stiff in social interactions or hyperactive. This hyperactivity is often manifested by parents wandering aimlessly around the nursery unable to sit still. The grieving person often demonstrates extreme self-centeredness, a sense of emptiness, lack of interest in things that used to be so important to them, and futility. An observer can notice symptoms such as confusion, disorganization, apprehension and poorly directed fear.

Grief reactions vary in intensity but are thought to be proportional to the amount of attachment formed between parent and baby. (Valentin, 1981, 1942). Also involved in this is the length and distance of separation as well as the child's prognosis. The grief process Kubler-Ross described can be witnessed in these parents whether or not the baby survives or does not. They still mourn the fact that they do not have a "perfect" baby if it lives, and if it does not, the parents mourn its death. The stages of this grief process are as follows: (1) Denial, (2) Anger, (3) Bargaining, (4) Depression, and (5) Acceptance. Nurses should be alert for parents who's grief may need more skilled guidance and help. (Kubler-Ross, 1969).

This grief reaction also shows a preoccupation with guilt which is the underlying emotion throughout these crises. (Tarbert, 1985, 22). Guilt feelings arise at the child's birth and persist for the rest of its life, many times unresolved. The statement, "What did I do to cause this?", is a recurring question put forth by these parents. After expressing this guilt many parents throw themselves into "doing" for the child. They are constantly searching for the right doctor, right treatment, etc. for their child.

Anger is another pervasive emotion exhibited in these parents. It is often manifested in these parents as the "Why me?" syndrome. (McGovern, 1984, 29). McGovern states, "The sick infant who is a source of worry to the family may evoke feelings of anger because of the pain he causes." Parents may direct this anger at the physician for the treatment the baby does or does not receive. More often it is the nurse who receives

the brunt of these angry feelings because she or he is has the most contact with the baby and the family.

Finally, the parents experience some degree of anxiety during the baby's entire hospitalization. (McGovern, 1984, 29) Parents fear for the child's life in the beginning and later for its optimum development in years to come. This anxiety sometimes exhibits itself in the early days of the hospitalization as a reluctance on the parents part to form an attachment with an infant they might lose.

## **PARENT/INFANT SEPARATION**

Because separation of the parents and infant is thought to have an affect on the bonding process, it would be best to address the issue of bonding or attachment first. Rivers describes the phenomena of bonding as:

... a unidirectional interaction from mother to baby. This has been hypothesized to occur over a short time interval—a 'critical period'—which is facilitated by skin-to-skin contact, suckling, mutual visual regard, and fondling. It has been suggested that 'bonding' is the basis for development of strong affectional ties between mother and infant without which their subsequent relationship may not be an optimal one. (Rivers, 1982, 170).

The capacity for attachment between infant and parents is thought to be found in a homeostatic state between the infant and his primary

caretakers. (Tarbert, 1985, 21). When the infant is in a life threatening state or is very premature, the immature status of the neurological system does not allow the infant to achieve a homeostatic state.

Because contact, especially physical, has been shown to facilitate bonding, the separation of the mother from the baby impedes this process. Separation affects not only mother-infant bonding, but both parents. (Valentin, 1981, 1942). Mother and father together and apart, have experienced thoughts of acceptance and excitement at the thought of having their baby. It is both parents who have hoped for the perfect child and feared a damaged unhealthy one; and it is both parents who must accept and adjust to the child born.

Valentin has identified twelve types of separation parents of a high risk newborn endure. (Valentin, 1981, 1942).

- (1) At the time of delivery, when the baby requires immediate resuscitation and instead of the physician or midwife handing the baby to mother, he/she hands the baby to the pediatrician.
- (2) When the baby needs to be taken immediately to the special care nursery.
- (3) When the baby requires transfer from the small referring maternity hospital to a large regional centre.
- (4) By the presence of doctors/nurses who are always in attendance on the baby and takes over its care.
- (5) By the actual physical separation by four walls when the baby is put into an incubator.
- (6) By the presence of equipment required to care medically for the baby.
- (7) Because the baby is so sick that he is unresponsive to his surroundings.
- (8) Because parents miss out on the limited amount of time in any day when any baby is awake and responsive.
- (9) Owing to the 'rules and regulations' common to most neonatal units.
- (10) Psychologically when the



baby is critically ill or severely deformed and may die—they try not to become too attached. (11) By distance of special intensive care nurseries from delivery and postnatal wards, from the parents' home or from the referring hospital from which the sick infant has been transferred. (12) By death.

It is obvious that almost all of the above reasons for separation are required to ensure the baby will receive the the highest quality of care possible. However, these can inhibit the bonding and attachment process.

The mother who is not allowed to see, touch, or hold her baby after birth will experience disappointment, loss, fear of abnormality, and fear of death of this child. (Valentin, 1981, 1942-3). The little time she does see her child will be spent watching the medical personnel perform life sustaining, yet frightening procedures. Further inhibiting the bonding process is the fact that the parents really never get to experience privacy with their infant and touching is often through the portholes of an isolette or between tubes and appliances necessary for the infant's life.

The bonding process is not limited to the mother and infant exclusively. The father's involvement at birth and thereafter has been shown to be of great importance in the father-infant bonding process. Research has demonstrated that a critical period exists for the father's entrance into the psychological development of his children. (Consolvo, 1984, 28). Fathers who were absent from their babies in early months of development have difficulty showing affection for them later. The

literature shows that fathers make unique contributions to their children's development, beginning at birth. These areas of contribution include sex-role identification, cognitive development, and general, psychological and social adjustment.

The father of a defective infant has a unique role of his own. (Thornton, 1984, 131). He is often the first to see the infant in the NICU and is responsible for communicating the bulk of information about the baby to the mother. He usually is expected to spend a great deal of time with the baby and often must visit alone. He has a sick baby and a recovering wife and must somehow maintain stability in the family. He often has two different hospitals to visit-usually far apart if the infant has been transport to a regional center for extensive care. Consolvo calls this role that of the "first family nurturer." (Consolvo, 1984, 28). This unanticipated role brings forth feelings of guilt because his first instinct is to be with his wife. Additionally, this accessibility to the infant and inaccessibility to the wife may cause the mother anger, guilt, or envy. The role of "first family nurturer" of the baby was one she had staked out long ago and at least for a while does not want to relinquish it when her bonding instincts are strongest.

Many fathers, feeling unprepared and apprehensive about this role often withdraw, becoming a bystander or absorbed with learning all the intricacies of the medical technology. (Consolvo, 1984, 29). Subjectively, fathers may feel anxiety, stress, but also dismay at some of the unsightly aspects of the newborn.

## FINANCIAL DIFFICULTIES

Emotional burdens are not the only ones parents with a child in a NICU experience. Financial difficulties can place an almost insurmountable pressure on some families. The families who are covered by a comprehensive health and hospitalization insurance program are the fortunate ones. However, this is often not the majority of the parents. Especially when one considers the exorbitant amount of money it costs to save babies. Lyon states that the hospital bill for very low birthweight infants or a child with severe anomalies can exceed \$100,000 in the first few weeks of life alone. (Lyon, 1985, 280). More specific examples of this cost follow: in Boston a 960 gram premature infant was in the hospital for 36 days at a cost of \$84,198. (Lyon, 1985, 285). In Los Angeles a baby born with a congenital heart defect, without surgery was hospitalized one month and the bill came to \$40,598. In a broader sense the United States spends \$2.65 billion annually on neonatal intensive care for 220,000 premature and malformed infants, or approximately \$12,000 per child. (Lyon, 1985, 285).

The financial burden for the parents does not often end with the discharge from the NICU. In the case of hydrocephalus, the procedure of placing a brain shunt shortly after birth can allow afflicted children years of prosperous life (Lyon, 1985, 283). But as they grow, additional surgeries will be required to revise the shunt to meet their new size--each surgery at a considerable cost. One child needed 23 separate shunt revisions!

One would assume that families who could not afford these high costs either through insurance coverage or "out of pocket" must be covered by some form of governmental assistance. Unfortunately this is true for only a small margin of the families in need. As Lyon states,

Society has evolved an incoherent and completely inadequate system of helping parents cope with these enormous expenditures. The financial supports that do exist either were devised to suit an earlier era, when medical and living costs were far below what they are now, or were intended as a safety net for the very poor, with scarcely a thought given to people of higher incomes. Furthermore, these supports make up a bewildering patchwork that varies from state to state. Within each state, programs exist inside a vacuum; there is little attempt to make them interlock, which leaves whole categories of conditions and entire economic classes to fall between the cracks. Scant effort is made to inform the general public as to what kinds of financial aid are available, so that parents seeking assistance are forced to stumble through a bureaucratic maze. (Lyon, 1985, 271).

There is a wide array of state programs in existence for parents who lack adequate health insurance, but these programs reimburse hospitals only to a limited expense and they are very selective about which families qualify. (Lyon, 1985, 271). Many states have what they call perinatal programs which will pay NICU expenses up to 30 days of

hospitalization. After that, the next step is to contact the state's Crippled Children's Fund. These programs, however, are quite selective about which diagnoses they will cover, and are excluding more and more afflictions as the funds grow scarcer. (Lyon, 1985, 272). If the state Crippled Children's Fund cannot be of help to the family they usually send them to Medicaid. But Medicaid has the stiffest financial eligibility requirements of all. Couples might receive income if their incomes exceed certain limits, but they will have to use any of their own resources first, including savings accounts, stocks and bonds, income property and they may even have to consign a confiscatory portion of their incomes to the state. The truly indigent families receive aid, but the middle class families are the ones hit the hardest because they do not meet the financial eligibility requirements even though they are in need. Lyon summarizes this problem by saying:

The fact is that middle-class families in the United States face economic disaster if they have a severely disabled child requiring extensive medical treatment. America's method of assisting them to gut their households and divest them of nearly every asset they have worked years to acquire, the avowed and inexplicable purpose being to reduce them to poverty. And this is done with a zeal approaching the punitive, as if it were somehow a family's fault that it conceived an impaired child, or as if having a few luxuries were a sin. (Lyon, 1985, 273).

## NURSING IMPLICATIONS

Because nurses have the most contact with these overburdened parents, they are also the most able to help them through the above stated crises and difficulties. Thornton believes the facilitation of coping with an infant in a NICU should begin before the birth if possible. (Thornton, 1984, 128). It is beneficial for the NICU nurse, physician, and social worker from the unit to introduce themselves to the high risk mother while she is in the obstetrics unit prior to delivery. This contact starts the process of orienting the parents to their infant's possible NICU course. Also helpful would be a tour of the NICU prior to a high risk delivery. This affords the parents a chance to see other infants of similar gestational age as their expected infant receiving similar care. Although this begins the period of adjustment, it is frightening for the parents.

Mothers delivering high risk infants in small community hospitals are not often able to be oriented to the regional NICU their child may be transferred to after delivery. The trend today is to transport the mother to a regional center prior to delivery. (Thornton, 1984, 128). This helps avoid early separation and allows for the preparation described above.

It is essential that a NICU nurse participate in the delivery of all high risk deliveries with the other team members. (Thornton, 1984, 128). This nurse should continue to care for the infant throughout his or her NICU stay on that particular shift. This not only provides more continuity of medical and nursing care, but also provides the parents with a familiar face with whom they may feel comfortable.

It is vital that at the birth the parents be exposed to the child, even for a short period. This is especially true when the child will be transferred to a regional center. (Thornton, 1984, 131). The family should be reunited with the baby, however short the time, before transport. This will give the family a chance to see and touch their baby and to make some connection--beginning the attachment process.

When the father first visits his baby in the NICU he is often overwhelmed and shocked. (Thornton, 1984, 131) Thornton has found it best to allow the father time to sit at the bedside and "take it all in." Remembering that the father is highly anxious and listening selectively, the nurse should use short, simple statements to explain the baby's condition and the equipment that is being used. She should encourage the father to touch and stroke the infant. This may help break the emotional barrier that the baby is "untouchable." As the father relaxes he will begin to ask questions which should be answered immediately and with honesty. It may be helpful to list some of the key information for the father. This reduces his burden of trying to remember everything he needs to tell the mother. When the mother of the baby first visits this approach should be repeated with her.

Recommendations have been made by Consolvo for nurturing fathers in the NICU. (Consolvo, 1984, 29). (1) Provide consistent information to ensure accurate communication between the father and the mother. (2) Point out attractive or positive aspects of the child to encourage interaction between father and child. (3) Encourage the father to be the "first family nurturer" explaining normal engrossment feelings of

new fathers and how they relate to his infant in the NICU. (4) Provide the father with a polaroid picture of the infant to give to the mother. (5) Point out the father's unique role in the NICU that he is one of few caretakers who provide touch which is not painful. (6) Educate the mother about the father's role and continue to acknowledge his role after the mother accompanies him.

As the parent or parents become more comfortable being near the baby the nurse should slowly explain what each piece of equipment is for and how it relates to the baby's condition.(McGovern, 1984, 29). If possible the baby's primary physician should also be present to further explain the infant's condition.

Parents of these babies need unlimited support by those that care for the child. (Valentin, 1981, 1943). They should never be treated as if they are "in the way." The rationale for all rules and regulations of the NICU should be explained to the parents. Counselling may be provided by a social worker, who can also help find solutions for economic and transportation difficulties. Those who care for the baby should never treat it as if it "belongs to" the hospital and not the parents, regardless of how attached they may have become to the infant. It should be remembered that the parents have the ultimate authority regarding their child. This feeling should never be endangered.

It is often difficult for parents in the NICU to actually fulfill the parental role. It is important for the nurse to facilitate parenting by allowing the mother and father as much control as possible. (Thornton,



1984, 132). Even though not medical experts, parents should be involved in the decision-making regarding their baby .(Thornton, 1984, 130). Involving parents in meetings with physicians, nurses, social workers and other personnel caring for their baby fosters the parents's self esteem.

Facilitation of parent-infant contact is important. The parents should be encouraged to touch and stroke their infant and to hold it as soon as medically possible. Other parenting activities such as bringing in toys, clothes, or religious ornaments should be greatly encouraged. Some parents record their voices or soothing music to be played for their infant. Others bring in photos of themselves and family members to line the isolette. These activities help the parents feel they are contributing to their infant's life, even in the smallest of ways. NICU's often have patterns available for "premie" clothes. Making clothes allows the mother an activity directly contributing to her baby. (Machan, 1983, 30).

It is also important to point out the normal features of the baby to its parents. (Machan, 1983, 30). Comments concerning parental resemblance can also be helpful.

The mother may feel helpless when it comes to caring for her child and may feel the nurses are more of a mother to her child than she is. One tangible act of motherhood that she can provide is breast milk. (Machan, 1983, 30). It is something she can "do" for the baby. The mother needs support and understanding during this time because, however fulfilling, long weeks of using a pump to express her milk can be emotionally draining without the interaction with her baby which this activity usually includes.

As the infant's condition improves, parents should be allowed to perform any caretaking activities they feel comfortable with. (Thornton, 1984, 133). These activities include bathing, feeding, and even rooming-in as the condition of the baby permits. When the parents are encouraged to participate they gain self esteem and confidence that will make the transition from hospital to home smoother.

Open visiting in the NICU remains an issue of controversy. (McGovern, 1984, 30). Parents, especially single mothers may benefit most from support of a close friend who may not be allowed to visit. Siblings, old enough to understand, would benefit from seeing and touching their baby brother or sister and would better understand what is occupying all of their mommy's or daddy's time. However, issues such as infection control and space limitations must be considered.

Information provided to families should be (1) a simple description of what has happened to the baby and what is happening to the baby currently; (2) if there is a clear reason for what happened the parents should be told; (3) likewise, if there is not a clear reason the parents should be told that as well, keeping in mind that they are probably blaming themselves; and (4) a description of the care planned for the infant in the next few hours. (Thornton, 1984, 130). Honesty and consistency are especially important when reporting information to parents. All credibility of the staff is at risk when parents receive conflicting information from different staff members.

Parental understanding of the infant's medical situation is of paramount importance. Not only is telling the parents what is wrong with

the baby crucial, but probably of greater value is assuring the accuracy of what the parents ' understand regarding their child's condition. (Mahan, 1983, 26) A good time to do this is during a family-physician conference by asking the family what they understand about the baby's condition. When misconceptions exist the staff need to make certain the family receives an explanation that will clarify their understanding.

Communication principles are an integral part of keeping the family informed as of the infant's condition. Many people are intimidated by the medical system and need encouragement to ask questions that they feel make themselves appear ignorant. (Mahan, 1983, 27). When answering parents' questions, it is best to avoid medical jargon. It is also advisable for the staff to help the parents prioritize the baby's problems as the parents rarely have enough medical sophistication to know which problem is more distressing.

When the baby is transferred to another hospital for treatment parents should be given the phone number of the unit and encouraged to call whenever they wish. (Valentin, 1981, 1943). Many units have a toll-free number the parents may be given, or a calling schedule can be used so that the parents avoid the fees by having the nurses call them.

On a more specific level, all medical personnel should introduce themselves to the parents before caring for the baby (when the parents are present). (Thornton, 1984, 128). Nurses should avoid the use of qualifiers when talking to the parents. Terms such as "very" sick and "most" infants are often confusing to distraught parents. Families may also attach

undue importance to such terms and be overly pessimistic or overly optimistic.

It is important to be realistic with the parents. This is especially important when the baby is unexpectedly transported to a regional NICU from a small community hospital. (Thornton, 1984, 130). This situation is more dramatic because of a lack of preparation and the long distance separation endured by the parents. Provide this family unlimited access to the unit by phone and in person when they are able to make the trip.

The potential for nursing in the area of discharge planning is great. Discharge planning begins when the baby is admitted to the NICU. (Julian, 1983, 34). At this time the primary nurse establishes goals for both the infant and the family. Julian states, "Discharge planning cannot be accomplished in one easy lesson. Rather, it involves assessing family needs, knowledge, and readiness to learn; planning the intervention itself; instituting the intervention and evaluating the effectiveness of the intervention." (Julian, 1983, 34).

In many units the baby's primary nurse fulfills the roles of discharge planner and teacher to the parents. (Lund, 1982, 50). In other units a full time discharge planner is responsible for seeing that discharge planning and teaching is accomplished. Even though one person is usually responsible for this, other disciplines such as physical therapy or occupational therapy may be involved. Coordination between disciplines is important to prevent the family from being any more overwhelmed than they already are.

Some parents are more able to assume the responsibility for caring for this infant than others. But no family should be judged incapable of adequate home care regardless of their education or socioeconomic level. (Lund, 1982, 51). Adolescent mothers as well as Ph. D. educated couples, in many instances are capable of caring for the baby with special needs. Each family should be presented with a thorough plan of what is expected of them as well as opportunities to learn in a comfortable atmosphere before their ability to care for the child at home is judged.

Discharge teaching involves the specific aspects of care the parents or primary caretakers need to know before the baby goes home. (Lund, 1982, 50). Teaching should begin after the baby's survival has been assured and the parents have resolved the crisis surrounding the birth. Specific areas of teaching for the parents of the neonate approaching discharge include general information regarding thermal regulation, feeding guidelines, and visiting recommendations; special diets and feedings such as gavage feeding and gastrostomy feeding; CPR techniques and the use of home monitoring devices; medication administration and in some cases, oxygen administration. One may see a more detailed listing of these teaching areas in "Discharge Planning for Infants in the Intensive Care Nursery" by Lund and Lefrak in the March/April, 1982 edition of *Perinatology-Neonatology*. (Lund, 1982, 56-8).

Many parents are offered the chance to "room-in" with their soon to be released baby for a few days prior to discharge. (Lund, 1982, 53). This allows the parents to "practice" caring for their child independently in a safe environment—one with physicians and nurses on call 24 hours a day to

answer questions and provide support. An area for transition for neonates who have been stabilized physiologically, but who are not yet ready to go home, has been developed by several hospitals. This was the topic of Goldson's article, "The Family Care Center" which discusses The Children's Hospital in Denver's approach to this type of transitional care. (Goldson, 1981, 17-19). This area helps the parents learn to respond to the baby's behavioral cues rather than relying so heavily on laboratory values and monitors to identify the infant's needs. This setting also provides an atmosphere where potential developmental and medical problems can be identified. At this center parents are able to gradually take over care of their infant with ample time and space for support and instruction from the nurses. Parents spend varying amounts of time in the center depending on their own schedules but are free to participate at any time and for as long as they desire. This environment also helps the parents form a more intimate relationship with the baby as they are now made aware of the fact that the baby is getting better and they can now begin to risk establishing a relationship with it.

Public health nurses can be extremely helpful in making this transition from hospital to home smoother. (Lund 1982, 58). This is especially important in families who are at a high risk for problems in caring for their infant at home. The public health nurse can act as a supporter and reference person to parents who are often overwhelmed by caring for their special infant.

Because these infants are often at a risk for developmental delays, follow-up care, specifically infant stimulation programs, are often recommended after discharge. (Tarbert, 1985, 21). In this type of program the parents, primarily the mother, is taught to provide developmentally appropriate activities that will hopefully enrich the child's neurological development. It has not yet been proven that these programs produce long term gains in motor development, but their worth as a means of mother-infant interaction in a developmentally appropriate manner is rarely questioned.

When referring a child to an infant stimulation program it is best to match the individual child's needs with the services available from the programs. (Tarbert, 1985, 20). The timing of these programs is also crucial. An individualized approach must be utilized based on the family's readiness to undertake the program. One must also consider the infant's needs regardless of the parents' readiness. These two areas must be weighted when deciding on the proper timing of the referral.

In the unfortunate, although not necessarily uncommon event that the baby does not progress adequately to discharge, but rather, dies, either at birth or at some point in his or her hospitalization, the parents need the support of someone who is aware of the effects this has on them and who can facilitate the grieving process. The baby's primary nurse or nurse taking care of the baby during that shift is a likely candidate because she has probably had more contact with the family than anyone else. Several considerations were presented in the literature for

facilitating the grieving process in these parents. (Mahan, 1983, 32). (1) The family should have the right to mourn in the manner that best meets their needs and staff personal biases should not interfere with this. (2) When talking with the family of a child who has died, at least one staff member familiar with the child should be present. (3) An opportunity to see, touch and/or hold the infant should always be made available. Parents should be allowed to spend as much time with this infant as they desire. (4) Parents should be allowed as much privacy with the baby as is possible. (5) A photograph of the infant after death should be offered as it may be the only picture they have with the baby free of tubes and machinery. (6) A chaplain of the faith the parents choose should be available. (7) Parents should be given all tangible remembrances of the child including name tags, arm bands, and locks of hair shaven for IV's. (8) Encourage the family to name the infant if they have not already done so. (9) Simple, concrete information regarding the funeral of an infant should be presented. Options available and financial aspects should be part of this explanation.

When talking with the family after the death remind them to call the unit if they have any further questions. (Mahan, 1983, 33). When they return home questions or concerns may arise as they become more emotionally stable. Families should be forewarned that the sadness they feel will exist for a long period but will substantially decrease over time. To help them cope with the death of their child many excellent books as well as parent support groups such as the Compassionate Friends exist.



Parents must also be warned of the well meaning, yet cruel remarks often spoken by close friends and relative in an attempt to comfort them. (Mahan, 1983, 34). "It was for the best" and "You can have other children" are often meant for the best but are devastating to hear. Other parents are simply avoided by friends. This is a common occurrence and it must be explained to the parents that it is usually because others do not know what to say.

Finally, a follow-up phone call or in-person contact is recommended after the death of a baby. (Mahan, 1983, 34). Parents may have questions concerning the illness and death, the autopsy report-if completed and questions about subsequent pregnancies. It is also important to talk with these parents to assess how the family is grieving and to check for signs of unhealthy grieving. Common reactions discussed earlier may need repeating and the family often needs encouragement to resume fun and social activities. This is often necessary because parents may fear it is disrespectful of the child to resume pre-crisis activities.

#### **USE OF SUPPORT GROUPS**

Most large regional NICUs have support groups available for the parents either through the hospital or through a private organization. Smaller cities, even those without regional centers, often have neonatal support groups available to parents. Marshall defines self help groups as "voluntary associations among individuals who share a common need or

problem and who seek to use the group as a means of dealing with that problem." (Marshall, 1982, 215).

These groups, in many instances have grown and become more established in the hospital and the community. Most of these groups have originated through the collaboration of veteran parents of high risk infants and professionals. (Marshall, 1982, 218). Groups such as "Neo-fight" in Carmel, Indiana, and "Parents of Pretermatures" in Seattle, Washington, offer such services as parent contacts with a veteran parent, monthly meetings, support regarding parental activities, such as breast feeding, educational materials, a hotline, and NICU fund raising.

A special support group has been formed to aid parents who have experienced perinatal death. A.M.E.N.D. (Aiding Mothers Experiencing Neonatal Death) has been established to aid grieving parents. (Marshall, 1982, 239). Each A.M.E.N.D. counselor is a parent who has experienced neonatal death. A.M.E.N.D. counselors must deal with their own loss and grief before beginning to counsel others. Most of the counselors have had subsequent healthy children.

Through this group parents are helped to resolve the death of their baby through sharing, counseling, trust, understanding and acceptance. (Marshall, 1982, 239). A.M.E.N.D. counselors are also becoming involved in community education to help the members of the community learn how to support the bereaved couple.

Parents also are involved in naturally occurring support groups in the unit, sometimes without really being aware of it. (Marshall, 1982,

217). Parents offer support to one another on a daily basis in the NICU dealing with setbacks, definitions of lingo used, and helping one another learn caretaking methods.

The primary nursing implication involved in support groups is for the nurse to be aware of their existence in her city and to refer parents she feels may benefit from participating in the group. The nurse can explain the purpose of the group to the parents and encourage them to attend. This may be the only way the parents become aware of the existence of support groups.

## CONCLUSION

When a newborn infant is admitted to the NICU the focus is on its problems and the care it needs. Equally important are the problems the parents experience and the assistance they require in dealing with them. If these needs are not recognized and addressed, future maladjustment in the bonding process as well as in the parents' marriage may occur. The nurse in the NICU and the nurse in the community hospital, if the baby has been transported, must be aware of the potential problems and difficulties these parents experience. They must not only be aware of the problems, but be willing to help the parents cope with them as they develop. When the parents overcome these problems or at least accept the difficulties presented, they are better able to function in their parental

roles. This will result in a healthier parent-child relationship. The nurses' responsibility in the NICU is thus two-fold: to the parents as well as to the infant and neither aspect can be neglected.

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